

# Massachusetts Developmental Disabilities Council 2009 Annual Report to the Citizens of Massachusetts

Our Mission: To provide opportunities for people with developmental disabilities and their families to enhance independence, productivity, and inclusion.

#### Table of Contents

- 1. Gopen Fellowship
- 2. Initiatives and Accomplishments
- 3. The Challenge Ahead
- 4. Performance, Accountability and Transparency

# What is a Developmental Disability?

A developmental disability is defined under Public Law 106-402, the Developmental Disabilities Act. Although the exact number is unknown, the Council estimates that over 117,000 Massachusetts citizens have a developmental disability.

# Gopen Fellowship Observes 10th Anniversary

2010 will mark the 10<sup>th</sup> Anniversary of the Gopen Fellowship. In partnership with our colleagues from the Massachusetts Developmental Disabilities Network – the Institute for Community Inclusion, Disability Law Center and the Shriver Center, the fellowship was established in 2001 to honor the memory of former Council Vice-Chairperson Barbara Gopen, a passionate and dedicated disability advocate.

The fellowship is a one-year program providing a unique opportunity for an individual with a disability or family member to work with and learn from a diverse group of disability policy professionals. In addition to implementing a project of their design, the fellow is educated about the disability system, advocacy, and disability policy on the state and federal level. Fellows have engaged in a diversity of projects including disability awareness, transportation, recreation, technology, self-advocacy leadership and multicultural outreach. Fellows have gone on to enhance their skills, including attending graduate school, serving as a Kennedy Fellow, and election as chairperson of a statewide self-advocacy organization.

Emily Rubin, the 2009 Gopen Fellow, implemented a project to enhance support for siblings of children and adults with developmental disabilities. Emily established a network of people interested in sibling support issues and produced a brochure on supporting siblings of explosive children.

For more information about the Gopen Fellowship and to obtain a copy of Emily's brochure, visit the Council website at <a href="https://www.mass.gov/mddc">www.mass.gov/mddc</a>.

### Massachusetts Alliance for 21st Century Disability Policy (MA21)

In collaboration with a network of statewide developmental disability advocacy groups the Council established the Massachusetts Alliance for 21<sup>st</sup> Century Policy (MA21). The mission of the alliance is to advance full community participation for people with intellectual and developmental disabilities.

The alliance produced a policy paper, "Implementing a 21<sup>st</sup> Century Disability Policy," which charts the vision of full participation and provides recommendations to advance self-determination and inclusion for people with disabilities. This publication was widely distributed to disability advocates, and it has reached a wider audience via website postings.

In the fall of 2009, the Alliance convened more than 100 advocates from across the Commonwealth to begin the work toward full participation. Regional groups have formed on a local and statewide basis to promote the Alliance's principles. The policy paper can be found on the Council's website at: <a href="https://www.mass.gov/mddc">www.mass.gov/mddc</a>.

### The Council

The Massachusetts Developmental Disabilities Council is pleased to present our third annual Report to the Citizens of the Commonwealth.

The Council's 2008 report was recognized with a *Certificate of Excellence in Citizen-Centric Reporting* by the Association of Government Accountants for a d v a n c i n g g o v e r n m e n t accountability. The Council was the first public agency in Massachusetts to receive this distinction.

Council members were again actively involved in initiatives to enhance independence, productivity and inclusion for people with developmental disabilities. To support written analyses and testimony conducted by Council staff, four members provided oral testimony to the state legislature in 2009 on the impact of proposed bills on the lives of people with disabilities and their families.

Council members also participated on task forces and committees in support of the Council, including the MA Building Blocks Advisory Committee, the MA Alliance for 21<sup>st</sup> Century Disability Policy, the Department of Developmental Services Statewide Advisory Council and the Statewide Independent Living Council. Many members also contributed their valuable time to the Self-Advocacy Leadership Series.

We want your feedback. Please contact us at:

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# Initiatives and Accomplishments in 2009

### What We Do: Our Primary Program Areas

The Council has four primary program areas. The **mission area** is defined by the Developmental Disabilities Act, and is the basis for all that we strive to achieve. The **functional area** divides the organization by our program and administrative activities. The **Areas of Emphasis** are defined by the U.S. Administration on Developmental Disabilities, and we report annually to the federal government under these program areas. Lastly, the **major activity areas** identify the program activities we undertake to successfully meet our five-year State Plan goals and objectives. These activities include efforts by Council members, staff, and sub-grantees, and our partnerships and collaborations with state agencies, non-profits, and disability advocacy groups.

The Council conducts ongoing customer satisfaction surveys and reports the results annually. Surveys are obtained from people with developmental disabilities, family members and other individuals involved with Council initiatives. The detailed survey asks respondents to rate the impact of Council supported initiatives, activities or projects. The Council maintained excellent results in all areas in 2009.

Customer Satisfaction

Respondents were satisfied with the activities they were involved with: 99.0 % Agreed, 1.0 % Disagreed.

That the activities helped better their lives: 98.0%, Agreed, 2.0 % Disagreed.

That they were treated with respect: 99.0 % Agreed, 1.0 % Disagreed.

# How We Measure Up by Federal Area of Emphasis

Areas of Emphasis are broad performance areas defined by the federal government. The Council undertook 45 initiatives in five areas initiatives through partnerships, collaborations and sub-grant funding, and also engaged in numerous partnerships and collaborative activities to educate policymakers and the general public about issues impacting people with developmental disabilities. In 2009, the Council met or exceeded 82.2% of its targeted performance measures within the Areas of Emphasis (37 of 45).

There were fifteen projects in the area of **Community Supports**, with two relating to **Housing.** The Council leveraged an additional \$108,943 to support these initiatives and 13,667 individuals received community or housing supports.

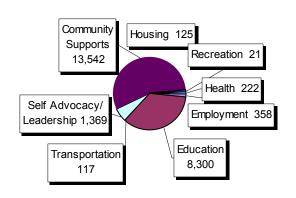
There were six projects in the area of **Education and Early Intervention.** 1,752 people were trained in inclusive education, 196 parents were trained regarding their child's education rights, and over 8,300 students received needed education supports.

There were five projects in the area of **Employment** and 358 adults with disabilities now work in jobs of their choice.

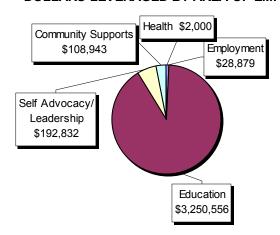
There were 10 projects in the area of **Self Advocacy and Leadership.** Over \$192,000 was leveraged for quality assurance programs, 217 people were trained in leadership and self-advocacy, and over 3,500 people and 77 partner entities were active in systems advocacy.

There were nine **Policymaker Education and Public Awareness** projects conducted to support activities in the related Areas of Emphasis. Over 1.2 million people were reached by the Council and partner public awareness activities, and 346 public policymakers were educated about the Council's priorities.

### PEOPLE INPACTED BY COUNCIL INITIATIVES



#### **DOLLARS LEVERAGED BY AREA OF EMPHASIS**



# The Challenge Ahead: Maintaining Key Programs

## Nationally Recognized Self Advocacy Program

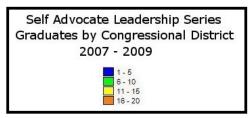


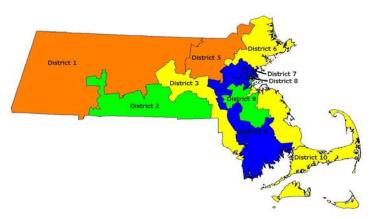
Started in 2003, the Council's Self Advocacy Leadership Series prepares people with developmental disabilities to serve as self-advocates and leaders in their local communities. The series is a 10 week program designed to teach the fundamentals of leadership and civic involvement. The class design includes lectures, role-play activities, and presentations and speeches by the students. There were 50 graduates in 2009, bringing the total to 101 since 2007. In 2009, an additional 32 people were unable to participate due to a lack of resources.

"I have been in this field for 30 years and of all the programs I have seen, this leadership series is by far the most beneficial for self-advocates." - A leader in self-advocacy.

The Council has designed a "train-the-trainer" curriculum and hopes to

partner with other advocacy groups in an effort to expand how often the program is offered to self-advocates across the Commonwealth. The Council is also developing a mentoring component to the program to help link graduates with new and potential participants.

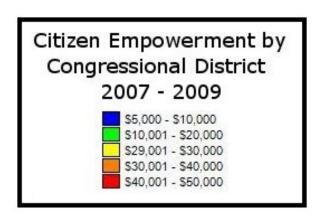


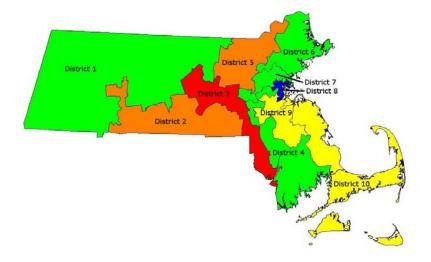


# Citizen Empowerment for Individuals and Family Members

The Council's Citizen Empowerment program provided over \$79,900 in 2009 to support 203 individuals with developmental disabilities and family members to attend conferences, trainings and workshops to gain vital skills for independence and inclusion. Participants contributed over \$6,700 in matching funds for the program. This investment continues to expand the network of committed advocates contributing to the community and supporting the Council's initiatives. In 2009 there were 193 families unable to use the program due to the Council's financial limitations. A workgroup of Council members is identifying ways to supplement the program allotted funds with other grants and contributions.

"This is such an important service to families like mine who often struggle financially due to the increased costs associated with raising special needs children." - A program participant





# Performance, Accountability, and Transparency

# **Primary Sources of Revenue**

Source of Revenue	2009 Revenue (in \$)
Federal Funding	\$1,249,097
Commonwealth Non- Financial Match	\$192,125
Sub-Grant Match	\$239,392
Developmental Disabilities Suite National Collaboration	\$217,340
Total Revenue	\$1,897,955

The financial mission of the Council is to maximize the usage of our federal awards, while leveraging additional resources from the Commonwealth, in partnerships, and with our grantees; to support meeting our five-year State Plan goals and objectives.

**Note:** The Council is funded through a federal formula grant and is authorized under Subtitle B of Public Law 106-402, the Developmental Disabilities Act of 2000, and through state Executive Order #512.

#### Independent Audit

The Council participated in the independent audit, receiving a clean opinion. Complete financial information is available at www.mass.gov/osc.

# **Primary Expenses**

Timary Expenses			
By Functional Area	2009 Expense (in \$)	By Mission Area	2009 Expense (in \$)
State Plan Implementation	\$1,449,913	Advocacy	\$777.373
Council Administration	\$230,702	Capacity Building	\$68,342
Developmental Disabilities Suite National Collaboration	\$217,340	Systems Change	\$555.367
Total Expense	\$1,897,955	Developmental Disabilities Suite National Collaboration	\$217,340
By Major Activity Area	2009 Expense (in \$)	Council Administration	\$279,533
		Total Expense	\$1,897,955
Self Advocacy	\$213,241	By Area of Emphasis	2009 Expense (in \$)
Citizen Empowerment	\$122,618	By Area of Emphasic	
Leadership Training	\$54,413	Education and Early Intervention	\$345,066
Legislative Education	\$65,887	Employment	\$83,799
Public Policy	\$769,974	Housing	\$83,798
State Developmental Disabilities Network Collaboration	\$174,849	Self Advocacy and Leadership	\$662,322
Developmental Disabilities Suite \$217,340	Community Supports	\$408,607	
National Collaboration		Educating Policymakers/Public Awareness	\$34,829
Council Administration	\$279,533	Council Administration	\$279,533
Total Expense	\$1,897,955	Total Expense	\$1,897,955

# About this Report

Each year the Council submits a Program Performance Report to the U.S. Administration on Developmental Disabilities detailing the advocacy, capacity building and systemic change activities that the Council has undertaken in an effort to meet its State Plan goals and objectives. The 2009 report is the third annual report for the current five-year State Plan. Copies of the full State Plan and Program Performance Report are available at www.mass.gov/mddc. Alternative formats of this report are available. We welcome questions and comments about this report. Please see our contact information on the front page of this report.

